

## Covid-19 vaccine survey results

Contact ran an online survey between 5 -17 March 2021. This was promoted across our network of families and parent carer groups. We have received 3000 responses.

Thank you to everyone that completed the survey.

## Recommendations

Based on the results Contact is calling on the government and the Joint Committee on Vaccination and Immunisation (JCVI) to:

- Prioritise clinically extremely vulnerable children for Covid-19 vaccines when they are licensed for use in children.
- Provide information on when a vaccine for clinically extremely vulnerable children will be rolled out.
- Expand guidance on which children can get unlicensed use of the vaccine and set up a process on how families and doctors can get unlicensed use of Covid-19 vaccines.

We also recommend amending existing guidance on 'main' unpaid carer to include all adults (including siblings) in the households with shielding or disabled children and young people. This will offer the most protection to clinically vulnerable children until a vaccine for them is available.

## Summary of key findings

- **70%** want their disabled children to have a Covid-19 vaccine when it has been licensed for use in under 16s.
- **10%** would like it off-label right now, but only **1.5% (3 in every 200 parents)** have been successful in getting it unlicensed so far
- Only **58%** of eligible disabled young people aged over 16 have been offered a vaccine.
- **79%** of disabled young people will have the vaccine when offered it, 18% are not sure, most due to being scared of needles or worried about impact on condition and only 3% said they wouldn't have the vaccine when offered.
- **Only 11%** of siblings aged over 16 with a disabled brother or sister have received a vaccine.
- **Less than half** (44%) of couples have both had a covid vaccine as unpaid carers, needed to protect their clinically extremely vulnerable children
- **60%** of those that tried to register as an unpaid carer with their GP as a way of getting the Covid vaccine in group 6 faced problems

- 86% of parents with disabled children have been offered a Covid-19 vaccine, 2 in 3 (67%) as an unpaid carers.

## **All findings**

### **Access for unpaid carers**

**86% have been offered a covid-19 vaccine** either as an unpaid carers (67%) or as part of another priority group (19%) e.g. as a health worker, age or underlying health condition).

**96% said they have had the vaccine or will do when offered it.**

3% unsure, mostly due to worries about side effects or safety.

Only 1% said they won't have it

This is really positive and shows high take up amongst families and why it was so important that Contact campaigned to get parent carers added to the priority list.

### **Couples and young carers over 16**

In married/co-habiting households, **45.5% both parents** have been offered the vaccine.

And **88%** of households with a non-disabled young person aged over 16, have NOT been offered the vaccine as a young carers.

The existing guidance indicates only the 'main carer' should be vaccinated under priority group 6. We would encourage the JCVI to revise guidance to say that all unpaid carers in a household including young carers over 16 should be offered the vaccine asap.

This would help provide better protection for families especially in households with clinically extremely vulnerable children who are unable access covid-19 vaccines.

### **Problems experienced getting a vaccine as an unpaid carer**

**60%** of those that tried to register as an unpaid carer with their GP as a way of getting the Covid vaccine in group 6 faced problems. Things included being refused, told not eligible as cared for a child, not main carer or GP unaware unpaid carers in priority 6.

Of those that have used the national booking system, 28% reported problems with the system.

### **Disabled young people**

**Only 58%** of disabled young people aged over 16 have been offered a vaccine despite the majority being part of priority group 4 or 6.

79% of disabled young people will have the vaccine when offered it

18% are not sure, most due to being scared of needles or worried about impact on condition  
Only 3% said they wouldn't have the vaccine when offered.

### **Siblings aged over 16**

11% of siblings aged over 16 and with a disabled brother or sister have received a vaccine

### **Disabled Children under the age of 16**

70% of parents want their disabled child (under 16) to have the vaccine when it has been through trials and is licensed for use by children

28% are unsure due to worries about impact on their child's condition and side effect and fears around needles for children with learning disabilities

2% said they did not want their child to have a Covid vaccine

### **Getting the vaccine unlicensed or off-label**

In some circumstances the Covid Vaccine may be used unlicensed/off-label for children under the age of 16 who are at high risk of becoming very ill if they get Covid. We asked parents if they had tried to get a Covid vaccine unlicensed.

- 1.5% have been vaccinated unlicensed.
- 8.2% said they have tried but refused
- 32% not aware of this route
- 58% not tried

### **Family experiences**

#### **Kelly hopes to be getting appointment for 15-year-old daughter Sophie's vaccine soon, but after several months of fighting for it**

Daughter Sophie, aged 15, has Mitochondrial disorder – she has a tracheostomy and high medical needs.

They have been shielding since March. They have kept their younger daughter at home, doing home learning, to protect her sister. It has had a huge impact on all their lives.

She said she was incensed when the government started saying that they were vaccinating the vulnerable, because there is a big group of children who were still shielding with no end in sight.

Once she saw information about chance of getting vaccine off licence for children in exceptional circumstances she started making enquiries. That was back in January and last week the metabolic specialist agreed she can have it. They are now waiting for correspondence from GP.

She feels it is a difficult process because no one is sure where the responsibility of it lies and this needs to be communicated better. Again, Kelly speaks very eloquently and powerfully.

### **Emma Lawrence from Brighton – refused vaccine for son Noah**

Son Noah, aged 13, has health and respiratory complications. When he gets a cold he has to have oxygen through adrenaline so they are very anxious that Noah could have serious complications from Covid. Noah goes to mainstream school but has not been in since March 5<sup>th</sup> last year. His brother Leo, who I think is in primary school, has also not been in as they have been shielding as a family.

She speaks very eloquently and emotionally about the impact that shielding for so long has had on the whole family. She said “I was distraught and physically shaking when the government said that all vulnerable people were being vaccinated.

Their MP Peter Kyle is supporting them to advocate for his need for a coronavirus injection. They have asked their GP about getting vaccine off label, and called 119. Yesterday Noah’s dad was told to take him to the local vaccination centre to try but they were refused. She said: “We’ve always been able to fix things for Noah and this is proving the most difficult.”

### **Quotes from parent carers trying to get vaccine off licence who completed our survey**

The comments left by parents illustrate the confusion and inconsistent approach being applied to unlicensed use of the vaccine for children with health conditions under the age of 16.

This may be because of confusion over the guidance, some GPs who are not as familiar with a child’s condition because they are under the care of a hospital or specialists may be reluctant to administer the vaccine to children 'off licence', uncertainty over where responsibility lies.

*I asked my sons consultant. He stated that he could not find information from Government which allows him to give the vaccine*

*My GP rang to ask as we have a high needs child age 12 she said check with paediatrician he say yes - now just waiting for date. Our doctors have been very supportive*

*Initially refused, but the latest Shielding letter up to 31st March 2021 stated that 12-15 year olds with neuro disabilities and have frequent chest infections can discuss it with their GP. I have discussed it - he has now said yes - but still waiting for CCG to confirm it. So he has still not had it yet - also the Pfizer vaccination was stated to be the one to have. Without the vaccination my son cannot go to school or access anywhere so could be shielding for another 3 years - already done a year!!*

*Have made many contacts regarding vaccines for under 16s and have been ignored by everyone. I guess no one cares if large numbers of children with special needs perish this winter*

*I have asked GP, consultants (multiple) and the CCG vaccination director. All professionals agree she meets the criteria for consideration for early vaccination (neurodevelopmental disability plus requiring residential care she has been unable to access for a year) but none of them are willing to make it happen. She's 16 in 4 weeks now and Gp has said she will be offered vaccine then. She's missed most of y10 and most of y11 and now online school is reducing because all her classmates are back in class. She cannot access face to face therapy she's give a year without physio or hydro abs has deteriorated massively physically and mentally - CAMHS are refusing to see her until she has been vaccinated.*

*Both my children are CEV, aged 14 and 11. I asked their clinical team if they could have the vaccine and was told not until they are 16 or when it's licensed for younger children*

### **In conclusion**

Contact is calling for clarity from the government on plans to develop and roll out a vaccine for clinically extremely vulnerable children and what steps parents need to take to get the vaccines unlicensed when this is agreed by parent, patient and doctor.

The JCVI must issue guidance to prioritise clinically extremely vulnerable and other disabled children for Covid-19 vaccines when it is licensed for use in children.

It would also be helpful if existing guidance on 'main' unpaid carer could be amended to include all adults including siblings in the households with shielding or disabled children and young people. This will offer the most protection to clinically vulnerable children until a vaccine for them is available.

Tens of thousands of clinically extremely vulnerable children have been left shielding and unable to return to school. Their families want and need information. Without access to a vaccine they have roadmap out of lockdown.

### **What you can do**

#### **SIGN OUR PETITION CALLING FOR A COVID-19 VACCINE FOR SHIELDING CHILDREN**

Read our [latest advice](#) on your questions about Covid vaccines

For more information about the survey findings please contact

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